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## ABSTRACT

This paper reviews the American Association on Mental Retardation's (AAMR's) presentation of issues surrounding the field of early intervention. AAMR's publications are the primary sources of information in the paper. Specific sections address: (1) the impact of public laws on the rights of children and families to a free and appropriate public education; (2) medical aspects of early intervention, including classification, definition, identification of children who are at risk for developmental delays, and genetic screening; (3) ethical concerns, including infanticide, right to life issues, and abortion; (4) prevention, at-risk children, adolescent mothers, and prevention programs; (5) developmental testing, IQ tests, and Down Syndrome studies; (6) international contributions; (7) early intervention programs and services; (8) family focused policies, barriers to services, and the costs of early intervention; (9) the education of professionals, physicians, and teacher certification programs; and (10) challenges facing the early intervention field. The need to document valuable intervention for young children and their families and innovative research initiatives and intervention programs that fulfill AAMR's mission to people with developmental disabilities is emphasized. (Contains 112 references.)  
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## EARLY INTERVENTION and PREVENTION - ISSUES AND SERVICES

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Early intervention research and programs have grown at an accelerated pace in the past twenty years since the passage of federal laws mandating such services. An important question posed by families, professionals and legislators asks: *is early intervention and prevention effective and cost-effective?* Is it cost-effective and beneficial to the child and the family (Guralnick, 1998; Swift, Fine, & Beck, 1985)? Conversely, Lacoste (1978) asked, Can early intervention hurt?

Early intervention involves developing beneficial partnerships with children and their families to enhance the well-being of the whole family during a time of stress and uncertainty. Services to infants and toddlers have developed into a critical part of modern supports for children and their families. Parents, educators, policy makers, medical personnel, and researchers understand that early intervention and prevention is important to families. A compelling rationale for early intervention services is that prevention is a promising approach for combating some of the consequences of developmental disabilities, i.e. secondary prevention. Although research clearly documenting the effectiveness of early intervention programs is not as precise as professionals and scientists want, early intervention does provide supports to children and their families without question. The medical aspects of early intervention highlight critical issues concerning identification, screening and evaluating, and genetic testing. The American Association on Mental Retardation (AAMR) remains an important voice in establishing the definition and classification of people with developmental disabilities.

This chapter reviews AAMR's presentation of medical issues facing the field, prevention

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of mental retardation, early intervention programs and services created, the education of professionals, and reflects on the challenges ahead (Table 1). AAMR's publications are the primary sources of information; many other valuable publications are also available. AAMR continues to provide conferences, publications, and critical legislative updates to its members concerning early intervention and prevention issues.

TABLE 1

KEY CONCEPTS OF EARLY INTERVENTION

- Impact of Public Laws.
- Medical Aspects: Classification, Definition, and Identification of Mental Retardation; Genetic Screening.
- Ethical Concerns: Infanticide; Right-to-Life; Abortion.
- Prevention: At-risk Children; Adolescent Mothers; Programs.
- Developmental Testing: IQ Tests; Down Syndrome Studies.
- International Contributions.
- Early Intervention Programs and Services - Will Early Intervention Help?
- Family-focused Policies: Costs of Early Intervention.
- Education of Professionals: Physicians; Teacher Certification Trends.
- The Future: IDEA; Prevention Efforts.

**IMPACT OF THE PUBLIC LAWS**

Public Law 94-142 greatly expanded the rights of children and families to a free and appropriate public education. Funding for children aged Birth to Three was added in subsequent reauthorizations, thus early intervention services grew exponentially. P. L. 94-142 focused primarily on the child and the educational services needed. With the passage of P.L. 99-457 and P.L. 101-476, Individuals with Disabilities Education Act (IDEA), the focus changed to a broader perspective including a more comprehensive evaluation of the child in his/her environment along with other supports for the family (AAMR: News & Notes, 1995). The emphasis shifted to a comprehensive system of support for families, not just educational programs for the special needs child. The entire family or household became the center of assessment. Along with this change, professionals providing services became more broadened in their practice, and case coordination services were also provided.

Mackie (1978), in a presentation at AAMR's 100th convention, discussed the foundation of special education changes for children with disabilities. Based on her many years at the Department of Education, Mackie chronicled the laws and research studies that have greatly influenced special education programs, grants, and the training of teachers.

## **MEDICAL ASPECTS OF EARLY INTERVENTION**

An important task of medical and intervention systems is to identify and assess children with developmental delays in order to provide appropriate intervention supports and services. Many of AAMR's efforts focus on this basic task. One aspect involves establishing, defining and validating criteria and refining the accuracy and reliability of the definition of mental retardation. In addition, AAMR continues to advocate for acceptance and dissemination of its definition in educational and public policy arenas. A comprehensive discussion by Zigler and others (1984) provided readers with strategic analysis of who should be labeled as a person with mental retardation. Zigler's article used two premises: that the definition of mental retardation relies on measures of intellectual abilities; and that the behavioral sciences have no better measure of intellectual functioning. The authors also concluded that not using a "label" of disability can result in a denial of access to governmental benefits and services.

AAMR, through its Committee on Terminology and Classification, researched and developed a revised classification system in current use (Luckasson et al., 1992). This revised classification system radically differs from previous ones because it does not include levels of severity based on IQ scores. Rather, the new system incorporates the actual level of functioning of the individual being assessed not the degree of mental retardation. Critics assert that this new system is based on 'referendum and affirmation' and not on scientific method. Reviewers also argue that an "adaptive skill level cannot satisfactorily represent intellectual functioning" (Jacobson, 1994, p.540). In addition, the 1992 definition recommends supportive and educational services practices consistent

with the assessment level reached. Ten domains of adaptive skills are utilized, however, testing materials which will be reliable and valid are still under development (Luckasson et al., 1996). This identification system remains an important contribution to the field of Mental Retardation and Developmental Disabilities, although much controversy surrounds the 1992 system which is a paradigm shift from a deficiency model to a support model (Schalock, et al, 1994). Concerns over the new system include its lack of precision to provide clear guidelines and thresholds for defining the upper level of mental retardation; its reliance on a team model to accurately assess a person with mild mental retardation; its problematic application to infants and young children; and its lack of reliability and specificity (Borthwick-Duffy, 1994; Greenspan, 1994; Jacobson, 1994; MacMillan, et al, 1993 & 1995; Reiss, 1994; Vig & Jedrysek, 1996). As part of its role in educating practitioners, AAMR offers training seminars in utilizing these materials.

Frankenberger and others conducted comprehensive surveys over a period of nine years analyzing State Department of Education definitions and procedures for identifying children with mental retardation (Frankenberger, 1984; Frankenberger & Harper, 1988; Frankenberger & Fronzaglio, 1991). Over the course of the studies, Frankenberger, et al discovered that the majority of states specified an IQ cutoff score above which a student would not be eligible for mental retardation services. However, many states deviated from AAMR's guidelines and procedures in identifying children with mental retardation. Also, there is little agreement in the states' methods of identifying deficits in adaptive behavior and academic achievement. Overall, the number of children receiving special services under the definition of mental retardation has decreased while the number receiving supports for learning disabilities has increased. The authors recommended that states include adaptive behavior and academic achievement assessments along with IQ scores to place a child effectively in special education programs. Another recommendation proposed using a multidisciplinary team to consider the standard error of measurement when using a specified IQ score of 70.

Categorizing children who are at risk for developmental delays is one component of the identification process. Ramey and co-authors performed a series of studies about predicting school failure from birth certificate information and identifying at-risk children, those children whose potential for developmental delays was rated high. Ramey et al. (1978) in the initial study predicted that information available on birth certificates can be used to predict educational and psychological status of first-grade children. The critical factors included race and mother's educational level. In 1980, a study by Finkelstein and Ramey predicted that by using a set of classification equations available on birth certificates, one could accurately identify first-grade children who would be considered as "educationally handicapped" when they reached first grade. The implications for early identification and intervention were encouraging. Ramey and Brownlee (1981) did continuing studies providing information on improving the identification of high-risk infants. The authors discovered that at-risk children could be identified by looking at psychosocial and environmental forces such as child's temperament, the mother's attitudes and the stability of the home. Ramey and Brownlee were able to accurately identify 80% of their study population of 25 who were labeled as "handicapped".

Identification is not a clear-cut process. In 1989, Myers presented information about the misleading cues in the diagnoses of mental retardation and infantile autism in preschool children. Common misconceptions could present confusing developmental and behavioral aspects leading to a misdiagnosis including: children with developmental delays may refuse to comply with requests; people commonly judge intelligence on apparent alertness to the environment; children with autism typically have normal body features; and normal gross-motor development is a predictor for normal intelligence. This list of common misconceptions may lead to an erroneous diagnosis and cautioned all mental retardation professionals to be conscious of the potential for misdiagnosis and incorrect labeling.

Procedures that review the effectiveness of identifying at-risk children at birth help in determining the accuracy of the definition of developmental delay. Two birth cohort

studies were presented in our journals. In an epidemiological study of live births in Canada, Baird and Sadovnick (1985) reported on the incidence of mental retardation. This study used the British Columbia Health Surveillance Registry which has access to 80 sources that identify individuals with mental retardation. This study used a substantial lag time and concluded that sufficient lag time is needed to accurately identify a child with a handicap, and identification is also related to the severity of retardation. In an age cohort of 15-29 year olds, an incidence rate of 7.7 % was identified. Katusic et al (1995) conducted a birth cohort review of a five year period in one Minnesota community to determine the incidence of mental retardation. Their study results matched other birth cohort studies in Finland and Sweden. The cumulative incidence of mental retardation by age 8 years was 9.1 per 1,000 children. One difficulty in predicting the incidence of mental retardation involves the lack of agreement on a clear and widely accepted definition of mental retardation.

West et al, (1992) developed a protocol to be used for the identification of children under the supervision of Child Protective Services. They discovered that child protective records provided poor information on health and developmental issues of children under its care. Their screening protocol would be useful for pinpointing potential problems and would "red flag" a chart to request a more in-depth evaluation.

Gindis (1986) discussed children with mental retardation in the Soviet Union using the Soviet's definition of disability which is: "A child is mentally retarded who has been consistently impaired in cognitive processing as a result of brain injury" (p. 381). Due to their view of disability as medically based and not using the social environment as a contributing factor, mental retardation is treated very differently. The Soviets do use a teamwork model but not necessarily a psychological evaluation. Special schooling typically begins at age 7. The authors remind us that all of us have a great deal to learn from our various intervention and identification systems.

## GENETIC SCREENING

Genetic screening provides an opportunity to prevent mental retardation and offer treatment for some diseases while also helping families prepare for the birth of their child. The Michigan Department of Mental Health established a genetic screening laboratory to provide diagnostic information to families of its service recipients. In its first two years of operation, 727 people were evaluated. Several patients received medical intervention which ameliorated some cases of "failure to thrive" (Theone et al, 1981). This study demonstrated that a state screening program can provide critical information to people, their families, educators and physicians about some causes of mental retardation.

An important ethical concern was reviewed by Peuschel (1991) who framed the ethical dilemmas of prenatal diagnosis of fetuses with Down Syndrome: should a diagnosis of a disability automatically lead to abortion or is this a threat to basic human rights? A quotation from Pearl S. Buck thoughtfully summarizes her feelings about abortions:

"A retarded child, a handicapped person, brings his own gift to life, even to the life of normal human beings. That gift is comprehended in the lessons of patience, understanding, and mercy, lessons which we all need to relive and to practice with one another, whatever we are. For this gift bestowed upon me by a helpless child, I give my thanks" (p. 188).

Umbreit and Ostrow (1980) provided a comprehensive report about fetal alcohol syndrome, including specific findings related to mental retardation and suggestions for early intervention services and social implications of the disease. These authors recommended preventive programs for both children and their mothers. Baumeister and Hamlett (1986) surveyed state-sponsored fetal alcohol syndrome programs to report that only a few succeeded and should be replicated in other states.

Two articles discussed the serious problem of lead poisoning - a preventable cause of developmental delay. Milar et al, (1980) showed that younger children with increased

lead levels experience deficits in their caregiving environment when compared with children showing no increased lead levels. The authors discovered that intellectual deficits previously attributed to lead toxicity may be related to a compromised home environment due to lower intelligence of mothers of young, high-lead children. The caregiving environment deficits were measured by the HOME Inventory - Caldwell's Home Observation for Measurement of the Environment. Hawk et al, (1986) replicated a previous study that studied the effects of interactive social environmental factors on the relationship of lead and IQ. There was a highly significant negative correlation between both lead levels and IQ scores, and closely linked to maternal IQ, home environment and gender. The HOME Inventory was evaluated by Adams, et al in 1984. The predictive efficiency of the Home Inventory was only moderately sensitive in identifying children in the low IQ groups among heterogenous populations.

Rogers and Simensen (1987) conducted a study of 67 persons with Fragile X Syndrome, which is the second most common etiology of mental retardation following Down Syndrome. The authors discovered that there is extreme variability in appearance and level of retardation; the diagnosis can be confirmed with cytogenetic testing; and that folic acid may be of benefit in the treatment of prepubertal Fragile X persons. In a special issue on prevention topics in *Mental Retardation*, Keenan and others (1992) reported on a statewide effort to increase public and professional awareness of Fragile X syndrome in New Jersey.

A special edition of *Mental Retardation* in August of 1989 provided a forum for a comprehensive analysis of programs, policies and services impacting children and adults with HIV infection. The articles originated from a conference on the subject sponsored by a consortium of federal departments and agencies serving people with disabilities, and the National Association of Protection & Advocacy Systems. Topics covered biomedical issues, developmental problems for children and adults, prevention programs, and legal and public policy issues affecting this population. The entire issue provides essential background information on HIV from key researchers (Crocker,

1989).

## ETHICAL CONCERNS: INFANTICIDE, RIGHT TO LIFE and ABORTION

AAMD Position Papers of 1973-1975 specifically mandate that people with mental retardation should never be denied treatment solely because of their handicap (Ellis & Luckasson, 1986). Even up to the 1970's, families and professionals needed to be warned about the unethical treatment of people with disabilities. Elks (1993) chronicled historical evidence that euthanasia may have been commonplace in some inhumane institutions, although unofficially, to eliminate the problem of "the feeble-minded." He quotes Malthus, the founder of population control, who recommended permitting unhealthy environments to specifically induce mortality to promote the early death of people with mental retardation.

In a sensitive and emotion-laden article, Hardman and Drew (1980) reviewed the legal, moral and ethical issues of withholding treatment from a severely defective newborn, discussed the role of the physician and parents' rights, and the issues of prolonging life versus euthanasia. This topic is still controversial. Affleck (1980) reviewed four studies of physicians' attitudes toward aggressive medical intervention of infants with Down Syndrome. He concluded that physicians expected that families with a handicapped child would disintegrate with a lessened quality of life. For this reason, Affleck justified less intense medical intervention for these patients. The myth of a decreased quality of life for families of handicapped children still prevails among some human service and medical professionals.

The February 1981 issue of *Mental Retardation* contained three articles addressing ethical issues. Wolf Wolfensberger (1981) contrasted the extermination of people with handicaps in concentration camps during World War II to current medical practices of withholding treatment, and to a prenatal diagnosis that leads to a therapeutic abortion. Wolfensberger explained that few opposed these extermination practices except the

pastors who ministered in those institutions.

Smith (1981) discusses Down Syndrome, amniocentesis and abortion. He postulates that Down Syndrome could be eliminated through therapeutic abortions. Smith urged AAMR to take a stronger negative stand on therapeutic abortion solely for fetuses with Down syndrome. Davis (1981) offers a constructive discussion on the use of amniocentesis associated with selective abortion. In 1996, the ethical and legal issues regarding selective abortion were presented by Glover and Glover. These authors concluded the issue is ethically problematic because a woman may obtain an abortion for a fetus based solely on the fetal diagnosis of Down Syndrome. The ethical issues arising from prenatal diagnosis are emotional and complex. This topic continues to be a subject of intense debate among medical ethicists, pro-choice and pro-life advocates, and parents. Self-advocates are also vocal about this issue.

In 1981, Stevens and Conn reassessed the ethical dilemmas concerning these topics. They concluded that pro-life decisions were more common and offered suggestions to improve the life-death decision-making process.

## PREVENTION

Prevention of Mental Retardation is a major goal for our organization. Two special issues of our journals were devoted to this topic. In March of 1984, AJMD's special issue highlighted the work of thirteen Mental Retardation Research Centers. Each center described its organization along with an article presenting one of its research studies. Michael J. Begab in his Guest Editorial wrote that an essential first step in any broad-scale program for the prevention and treatment of mental retardation is a full understanding of its cause and pathogenesis. Ramey and Campbell (1984) studied a group of 54 at-risk preschool children enrolled in special education programs. Their preschool intervention program helped those children maintain national average scores on standardized developmental tests when compared to a control group not receiving early intervention services.

Volume 30(6) of *Mental Retardation* (1992a) also focused on prevention. Dr. Allen Crocker's guest editorial reflected on what had been learned from 20 years of research and practice in the field. Major themes in this special issue included evaluation and accountability, interrelated factors leading to developmental delays, community activities, preventing secondary conditions and the importance of education. Another article by Crocker (1992b) presented an evaluation technique composed of forty-three indicators used for measuring the effects of prevention programs. Prevention activities need to look at the whole of a child's life including social, environmental, educational, and medical concerns. Adams & Holowell (1992) writing about community-based projects for the prevention of Developmental Disabilities discovered that prevention programs stimulated effective community involvement. In evaluating the programs offered in twenty-eight states, the authors determined that many programs failed to accomplish their mission. Coulter (1992) proposed that our thinking about how mental retardation is conceptualized has radically changed from a medical/disease model to one where we view how the person functions in his/her own environment. He found that many articles in the special issue took this ecological/holistic perspective on prevention. The exemplary information in this issue is well worth reviewing.

Predicting and understanding developmental delays in children of adolescent mothers was presented by Whitman, et al in 1987. Constructs contributing to developmental delays in children included a wide variety of social, economic, personal and environmental factors. These factors were descriptive at best, but three critical factors thought to predict later child development included: personal characteristics of the mother including maternal intelligence and readiness for parenting; the surrounding social milieu including social support systems and socioeconomic status; and characteristics of the infant's neonatal characteristics and meeting developmental milestones. These factors need to be considered in the development of early intervention programs for this population.

Coulter(1991) and Drash (1992) debated the failures of prevention programs. Coulter

stated that prevention efforts have not significantly reduced the prevalence or severity of disabilities. According to Coulter, programs fail because they do not consider the interrelationships of all of the environmental, educational, behavioral and biomedical issues involved, and because we do not know the causes of mental retardation. Although some causes of mental retardation are known, we still cannot prevent the outcome of disability. Drash strongly disputed Coulter's argument and wrote that this was an inaccurate assessment of prevention programs. In his retort, Drash presented arguments to counter each of Coulter's claims and then developed a comprehensive plan to ameliorate functional retardation.

Sells and Bennett (1977) reviewed 100 years of medicine's role in the area of prevention, causes and treatment of developmental disabilities. They concluded that striking progress in the areas of human genetics, factors affecting pregnancy, newborn screening and postnatal interventions. They recommended that the skills of both medical and social scientists are needed to discover the causes of mental retardation and to devise in order to prevent it. Luckasson, et al (1996) who are the classification system authors, also recommend connecting the etiology of mental retardation to aspects of prevention. The authors conclude that in order to provide the most effective intervention plans for individuals, consideration of prevention paradigms need to be considered. The research continues.

## DEVELOPMENTAL TESTING

Testing of intelligence and assessing developmental milestones is at the core of identification and placement of children with disabilities. Testing has always been controversial when used to be predictive of outcomes and successes. In addition, testing is flawed by variables such as the tester's ability, the child's emotional state, and the many environmental influences. Many articles, throughout these twenty years of AAMR's publishing history, debate the effectiveness of various intelligence assessment tools. Scales evaluated included the Bayley Scale of Infant Development, Caldwell Home Inventory, Catell Infant Intelligence Scale, Revised Denver Developmental Scale,

Kaufman Assessment Battery for Children, Stanford-Binet Intelligence Scale, Uzirigis-Hunt (Piaget-based) Scale, Vineland Social Maturity Scale, and Wisconsin Behavior Rating Scale. Articles compared, contrasted and evaluated predictive reliability, mothers' influence on testing, accuracy of predictive ability to determine future IQ scores, and how test results should be regarded. If test scores could be questioned for reliability and validity in accurately evaluating children, then how can we rely on them for determining the most appropriate program placement? Assessment testing involves much analysis, training and also means collaboration with families (Atkinson, 1990; Bloom et al, 1988; Bradley & Caldwell, 1979; DuBose, 1977; Haskins et al, 1978; Naglieri, 1981; Nugent, 1976; Song & Jones, 1982; Wachs, 1978; Wilson, 1992). A meta-analysis of infant intelligent scales was conducted by Hatcher in 1976. He concluded that studies of reliability have been favorable; IQ levels between infant tests and school-age tests are widely varied; and that including environmental factors in conjunction with infant test might lead to increased predictability in accurate testing levels. The second edition of the Bayley Scales of Infant Development was critiqued by Robinson and Mervis (1996). These authors provided revised extrapolated tables of the scales in which improved components were noted.

More than 100 articles, monographs and books presented findings on how infants and preschoolers are evaluated for various social and developmental abilities. Many publications presented critical findings concerning language development, teaching language skills, and evaluating acquisition of language. More than thirty-five reports presented information about: maternal speech patterns, different teaching methods, evaluating language acquisitions in integrated settings, communication between teachers and their students. Social skills articles reviewed observation of classroom behavior, adaptive behaviors, teacher ratings, mothers' ratings, attention span and affective behavior. Developmental skills studies described cognitive play in home and school, symbolic play, long-term memory, motor skills, feeding milestones, interaction with moms and toys, and mother versus teacher rating of adaptive behavior. One study compared the use of observation measures by parents versus formal testing

procedures (Hanson, Vail & Irvin, 1979). Results demonstrated that parents are reliable observers of infant behavior. It is rewarding to come across data that substantiates our intuitive knowledge.

Approximately twenty-five articles presented findings about early intervention issues on Down Syndrome during this twenty year review. These articles noted that children with Down Syndrome are diagnosed early and are subsequently subject to intervention services at an early age. As a group, these infants and toddlers were evaluated for social, adaptive, language and cognitive skills, affective responses, attention span, mothers' attention to language using infant intelligence scales, and innovative testing methods.

Many articles discussed teaching techniques, rating them on effectiveness and ease of use. A meta-analysis of Gentle Teaching techniques was published by Mudford (1995). Gentle Teaching philosophy focuses on errorless learning, task analysis, response prompting, co-participation, identification of antecedents, fading prompts and condemns applied behavior analysis. This author recommends using Gentle Teaching techniques with caution due to the inconsistencies and unproven efficacy of their evaluation techniques. He concludes by warning of the potential negative impact of this teaching technique. Mothers' teaching styles were evaluated by a few authors. Filler and Bricker (1976) determined that the behavior of children controls the reinforcing aspects of teaching style. One other article discussed coaching mothers on developing more positive teaching styles with their infants to reduce the amount of stimulation needed for positive responses (Seifer, Clark & Sameroff, 1991).

Inclusion and integration, once considered controversial topics, were examined by Childs in 1979. Childs questioned whether the movement away from a survival skills special education curriculum to a "watered down" regular academic curriculum for special needs children was effective. He argued that his research did not lead to support of an academic curriculum. This particular article led to many responses from

major contributors in AAMR including Sue Allen Warren and Burton Blatt (1979). However, their responses focused on educable children in mainstreamed classrooms and did not include the field of early intervention.

Payne, et al (1979) summarized the National Association of Retarded Citizens' (now known as The Arc) 1977 policy guidelines for school systems. The authors summarized 200 concerns about mainstreaming's impact on the child with developmental delays in the regular classroom. Blacher-Dixon, Leonard and Turnbull (1981) presented an in-depth analysis of the impact of mainstreaming at the early childhood level. They reported that mainstreaming at the preschool level for mildly affected children has been shown to be advantageous, but the precise factors required for success were not clear. The authors concluded that more research is still needed to validate this approach for young children that will open up many more opportunities and services for special needs children in the school system. Articles in later years focused on the benefits of social interaction of integrated preschool settings.

## INTERNATIONAL ISSUES

Membership in AAMR is international and diverse. International perspectives about diagnosis, etiology and genetic causes of mental retardation have provided valuable contributions to many issues. In an etiological study of mental retardation in Hungary, Czeizel et al, (1980) classified 50% as "pathologically retarded" and 50% as "familial-culturally retarded". The researchers completed a comparative analysis with three other studies and found similar results. Etiology of mild mental retardation among Bahraini children was published by Al-Ansari in 1993. In this developing country, the prevalence rate of mental retardation was 9.8 per 1,000 population. By documenting the causes of mental retardation, this author was hoping to initiate prevention strategies. The Chernobyl Nuclear Catastrophe was discussed in relation to its impact on the health and high risk potential for mental retardation of children born to victims (Holowinsky, 1993). Irradiation, as an etiological variable in mental retardation, has been studied and documented since the 1920's. The author ascertained that the prevalence of retardation

is related to the definitions and terminology used. Funds from the World Health Organization to study this issue were frozen and never restored to explore this problem.

## EARLY INTERVENTION PROGRAMS

Throughout this 20 year review from 1976 to 1996, AAMR has published a wide range of information about early intervention services covering efficacy, administration, and influence on children's lives. The first questions families ask include: Will early intervention help?; Will it prevent further delays?; Will our child catch up?; How can we ensure our child receives the best possible program that will improve his/her condition? This section highlights some of the major thinking about these questions and programs.

In 1977, Brassell used words that were cautious and tentative in describing the impact of early intervention services. He called these programs "a promising approach ... with encouraging effects ... that may be predictive of the efficacy of services" (p. 18).

More recently, results clearly show that the impact of early intervention services are correlated to positive outcomes for children and their families. "Results suggest that early childhood education has been instrumental in assisting the cognitive development of young ... children" with cognitive impairments (Ramey & Campbell, 1979, p. 647). Many times, testing involved comparison groups of children and determined that those receiving early services demonstrated improvements in many developmental milestones. Services for psychosocially disadvantaged children clearly led to improved abilities in attending, comprehension, and abstract thinking skills, and improved on Bayley scores (Ramey & Smith, 1976).

The March 1991 edition of the AJMR published five articles about The Milwaukee Project related to this 15 year-long study of the impact of early intervention programs for disadvantaged mothers and their children from impoverished neighborhoods (Garber et al; Guthrie; MacMillan & Widaman; Spitz; Weinberg). In addition, AAMR also published the monograph describing the project (Garber, 1988). Much controversy surrounds the

entire project including methodology, results obtained, conclusions reached, and legal charges regarding the fraudulent use of money. These articles provided extensive criticisms of the published monograph along with Garber's response to these critiques. The project was aimed at modifying the experiences of at-risk newborns whose mother's IQ scores were 75 or lower. Infant stimulation and family training were provided over a 15 year period. Two control/contrast groups were established to compare the interventions. Based on the number of major flaws in carrying out this project, the results should be viewed with skepticism. The statistical results were striking showing consistent significant differences between the experimental and control groups. Thus, the hypothesis that low-intellect mothers will have low-intellect children if no remedial intervention is provided was clearly validated in this project (Guthrie, 1991).

In the special issue on prevention, Ramey and Ramey (1992) substantiate findings that intensive early intervention services explicitly lead to improved lives for children with disabilities and have long-lasting impact on these children's lives. Sharav and Shlomo (1986) presented results of early intervention services in Jerusalem for 51 children with Down's Syndrome. Early intervention services demonstrated that infant stimulation programs along with home training improved the functioning level of the children in both short-term and long-term abilities. In addition, emotional support for families was an essential component of the program. Brassell (1977) studied an intervention program for 73 infants with disabilities and found that psychosocial variables and developmental milestones were closely related. Ninety percent (90%) of infants who showed substantial improvement had high maternal interaction rates. In addition, more progress was noted in infants with milder delays. Head Start programs have also added to the social competence of economically disadvantaged children (Zigler & Cascione, 1977).

What does early intervention cost? How can administrators estimate costs per child based on the level of need? Erickson (1992) analyzed the expenditures for a broad range of children to determine the costs associated with implementing the early intervention components of P.L. 99-457. Wide variations were found for variables such

as center-based and in-home services, hours of service received, type of services received and cost of services. The costs ranged from \$1500 to \$11,000 based on service types, total hours of service received and the degree of the child's handicap. Valuable analyses of data clearly outline the enormous variability of range and costs per service.

In the field of education, there is no one best practice approach for all children, although incidental teaching is an important technique used. Programs need to encompass comprehensive and coordinated services so that families and children receive all that is required. In addition, involving the whole family in the program and the development of the IFSP (Individual Family Service Plan) ideally leads to a more comprehensive program and enhanced life for all involved. The auxiliary role of the professional is to provide resources and support (McWilliam & Bailey, 1993).

Families who have children with disabilities are first of all families with differences and strengths. Mahoney and O'Sullivan (1990) surveyed early intervention programs to assess their efforts at changing from a clinical child-centered model to one encompassing the whole family. They concluded that programs had not yet fully incorporated the changed philosophy behind P. L. 99-457 as of their publication date. Early intervention programs need to incorporate a family-focused agenda which integrates families into their clinical intervention programs. In addition, service providers who lack experience and academic preparation for work with families inhibits family program development. More training and administrative support are needed to provide comprehensive family-directed programs.

Families face many problems when they are trying to locate appropriate early intervention services and then decide whether a specific program fits their child's needs. Families are torn when trying to determine the best possible intervention for the child and for the family as a whole in light of insurance limits, school regulations and cost of care (McWilliam & Bailey, 1993). Many times, children who are placed on

waiting lists are forced to wait too long for these essential services. We also need to be aware of drawbacks to early intervention programs. Inappropriate reassurances to families saying that an early intervention program will "cure" a child's diagnosis provide false hope. In this field of practice, we can attest to prevention results and improvement in many abilities but "curing" a condition is not a supportable presumption. Misdiagnosis and the impact of the programs themselves may lead to poor mother-infant bonding with the family (Lacoste, 1978).

Early intervention services are a collaborative process combining the best of care for the child and family from the professional community, the educational system and our social welfare policies. Our work motivates us to keep striving to develop more effective early intervention programs.

## **EDUCATION OF PROFESSIONALS**

Very few articles discuss the training of physicians, although other reports indicate that the need for effective identification of children is primarily through the efforts of medical personnel. Richardson, et al (1978) assessed an innovative pediatric training program designed to overcome the lack of exposure of medical students to children with disabilities. Through self-report, these students indicated that both their competence and confidence in relation to each program objective increased due to their participation in the training program. Wolraich (1979) suggests that a one month training program in developmental disabilities for pediatric residents leads to increased knowledge, development of a more positive attitude toward such children, and improved interpersonal and counseling skills needed when working with parents. Epps and Kroecker (1995b) recommend requiring medical students to interact more actively with such children and their families. Medical education should include rotations at a child development and mental retardation services agency, and observations of early intervention and special education programs.

Scheerenberger (1979), AAMR President, discussed the organization's new certification program in continuing education for professionals. AAMR required 150 hours of continuing education credit in various categories. The Continuing Education Certification continues to be valid for three years. Currently, the Certification program requires 75 hours of approved continuing education credits.

Teacher certification trends were presented by Russo and Stark (1976). They surveyed all states and the District of Columbia asking about teacher certification in the area of severe and profound handicapped children. The authors reported that only four states offer a specific category for severe/profound handicapped certification. Seven states anticipate offering this type of certification, while six states believe a need exists but do not provide such a certification. Twenty-three states did not plan to initiate any special certification in specific categories. However, most states had specific requirements concerning state certification in special education. They included: specific academic courses; knowledge of growth and development and deviation from normal stages; behavior management skills; diagnostic and prescriptive skills; educational planning and curriculum development; and planning and coordination programs for parents and teams.

Milne (1979) surveyed teachers and administrators to find out what were the most critical needs in the preparation of teachers. Results indicated that teachers need to demonstrate competence in learning activities, pupil self-concept, pupil self-discipline, communication development and parent interaction domains. In addition, the respondents believed that a greater degree of field experience in teacher training programs would be beneficial. Sterns and Jarrett (1976) surveyed Schools of Social Work to determine the content of materials on Mental Retardation offered in graduate programs. Respondents from 54 schools showed that only seven schools (13%) offered courses specifically on mental retardation; nineteen (35%) stated that mental retardation is a specific area of interest but offer no courses on the subject.

## LOOKING AHEAD

Baumeister (1981) expressed disappointment in the wide gap between the scientific knowledge we possess and how we practice - the difference between what we know in this field and how social policy lags behind the expertise we exhibit. He makes a cogent moral argument calling for program evaluation for every service offered along with "ordinary knowledge" - knowledge discovered through lived experiences, intuition, common sense and personal values.

A FORUM article by Senator Tom Harkin (1990) presented the history and processes concerning the reenactment of Individuals with Disabilities Education Act (IDEA). Senator Harkin was an instrumental advocate in the passage of the Americans with Disabilities Act of 1990 and IDEA. He acknowledged that parents and professionals played key roles in testifying in support of the legislation and in helping Congress to expand key services. IDEA expanded grant programs to serve infants and toddlers, school-aged children and preschool children; emphasized a team approach in assessing child and family needs; and ensuring adequate personnel training for staff (AAMR- News & Notes, 1995). Stanley Herr (1997) called IDEA the "Magna Charta for children with disabilities and their families" and a landmark piece of legislation in his statement in the reauthorization hearings for IDEA.

The President's Committee on Mental Retardation sponsored a summit and published a report on *The National Effort to Prevent Mental Retardation and Related Disabilities* (1993). This material was prepared by one of AAMR's key members in the field of prevention - Allen Crocker, M.D.. The report describes critical issues in the national effort to minimize the occurrence and ameliorate the effects of developmental disabilities. Duane Alexander, Director of the National Institute of Child Health and Human Development (NICHD) at the time of the summit, spoke of the future directions in prevention work. His list included gene replacement therapy, fetal therapy

through prenatal surgery and intrauterine transfusion, and neurobiology relating to the programmed development of central nervous systems and regeneration of nerve cells in the brain and spinal cord. New hazards and challenges include the children born to drug-addicted mothers and "crack babies" entry into schools. Alexander (NICHD) hoped future research would offer the following: that better and more precise diagnoses of children with developmental disabilities would be available; that the major causes of genetically determined mental retardation would be identified at the gene level through DNA studies; that birthing procedures leading to a reduction of the serious consequences of brain oxygen deprivation would be developed; and that better comprehension of the biological basis of learning disabilities would be established.

The findings of an intensive early intervention program were summarized by Fewell and Glick (1996). Intensive programming helped all children to maintain developmental milestones while more significant gains were achieved by less severely handicapped infants and toddlers. The authors emphasized that research results clearly affect social policy and the funding for programs and services. "Should the potential for progress be considered in determining who gets early intervention?" (Fewell & Glick, p. 239). If early intervention professionals and families do not get involved at the policy level, *others* will be making critical decisions concerning what type of services are offered and who will receive these services. All of us need to become active players in the political agendas of policy-making, decision-making and the overall political process of setting social agendas.

Major accomplishments concerning early intervention programs, research and services have been achieved over the twenty years reviewed in *Embarking On A New Century*. Together, we have documented valuable interventions for young children and their families, and we must continue to document innovative research initiatives and intervention programs that fulfill AAMR's mission to people with Developmental Disabilities. The organization supports research projects, publications and conferences aimed at learning about prevention, identification and classification of people with

mental retardation and developmental disabilities including establishing the definition of Mental Retardation. AAMR must continue to support researchers and practitioners in the development of new information, technology, and interventions concerning infants and toddlers. AAMR could expand its resources on access to specific information. For example, website locations regarding funding sources, model programs, and conferences on special topics could be made available on AAMR's website. The organization could offer additional regional conferences or teleconferences on specific topics and provide keynote speakers for the seminars. AAMR remains and will continue to be an important publisher of materials on special topics using its valuable resource - its members. Early intervention was initially viewed as a promising approach with encouraging potential. We still have far to go. Together - families, children with mental retardation, professionals and AAMR - have made a difference but we must continue to uncover new developments and interventions.

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